



THE PARKINSON'S AND MOVEMENT DISORDER FOUNDATION

Newsletter  Summer 2015

The Parkinson's and Movement Disorder Foundation

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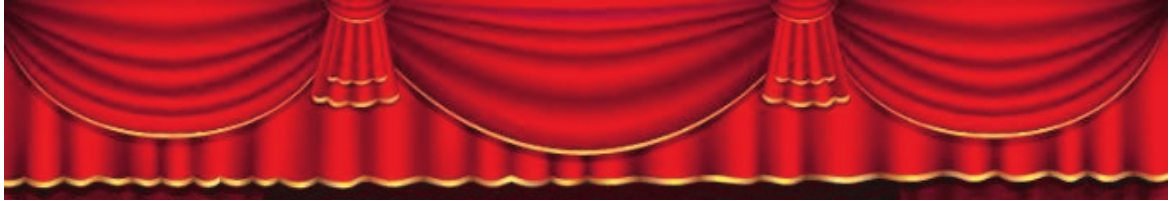
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PMDF presents *The 2015 Hollywood Premier Night & Silent Film Gala*



Are you ready for an event like no other? On Sunday October 25, 2015, The Parkinson's & Movement Disorder Foundation will present its spectacular *Hollywood Premier Night & Silent Film Gala* at the prestigious Brea Civic & Cultural Center in Brea. Come dressed as your favorite movie star or character as the PMDF takes you back to a nostalgic 1920s/1930s evening of Hollywood's glorious heyday.

The evening will begin with an exquisite dinner brought to you by the award-winning Fullerton-based Colette's Catering Extraordinaire, with music and silent auction.

But the evening has just begun!

Following dinner, you will be transported to Brea's plush Curtis Theatre for a night of early Hollywood film comedy and music. The evening will feature a screening of the 1924 silent film comedy classic, *Girl Shy*, starring the legendary Harold Lloyd. Lloyd ranks alongside Charlie Chaplin and Buster Keaton as one of the most popular and influential film comedians of the silent film era. From a 2004 *OC Weekly* write-up of Harold Lloyd:

Long before Jackie Chan began do-

ing stunts that could easily cripple a man a third his age, Harold Lloyd was risking life and limb to give his audience a few chuckles. Lloyd flourished during Hollywood's lawless days; it was an era before union regulations, when on-set safety was barely considered and directors routinely subjected their stars to actual raging fires and pounding floods. Special effects were so primitive that when guns were fired onscreen, well, guns were fired onscreen. And even against this backdrop, people thought Lloyd was nuts for the stunts he did in his pictures. Even the most jaded modern audiences are won over by Lloyd's brash, exuberant charm, and when one of his action sequences is in full flight, you are very much in the moment; in fact, you are short of breath both from laughing yourself hoarse and from the suspense of wondering how the heck Lloyd will get himself out of this latest mess. *Girl Shy* stars Harold Lloyd as a sweet, stuttering, impoverished geekboy who falls hard for a lovely rich girl. The film zips along at a breezy pace, but nothing prepares you for the 20-minute chase *Continued on page 3*

President's Letter



Dear Friends of PMDF,

As you have probably noticed, our Fall Fundraiser is coming up, and it's going to be another fun event. This year we have an "old Hollywood" theme, with live music and a classic silent film. You are encouraged (but not required) to dress for the era or come as a favorite movie star. Come join us to support research to create a world without Parkinson's and all movement disorders.

Our Spring Fundraiser, the Zent-a-Thon, was a big success, netting over \$10,500. Over 120 people attended the event. A big "thank you" to our corporate sponsors Lundbeck, Merz Pharma, and UCB, to the Katella Deli for the food, to the Saigon Television Foundation for the drinks, and to Dr. Truong for the T-shirts. And further thanks to the Zent family for their work in promoting the event and encouraging attendance.

If you or a loved one has Parkinson's disease, you might be interested in Tremble Clefs, a therapeutic singing group for people with Parkinson's disease. The members get together for 1½ hours each week. At these meegings, the participants warm up with voice exercises that specifically address issues pertaining to people with Parkinson's, then proceed to singing a variety of pieces. The group gives performances about every six to eight weeks. Tremble Clefs is free, and family members are welcome to participate. I started going to the North Orange County group early this year, and I've really enjoyed it. There are two groups in Orange County and two in San Diego County. See [http:// http:// www.parkinsonsassociation.org/tremble-clefs/](http://www.parkinsonsassociation.org/tremble-clefs/) or contact the director, Karen Skipper, MT-BC, at ph. 949-496-1756 for more information.

Sincerely,

A handwritten signature in dark ink that reads "Mark Wadsworth".

Mark Wadsworth
President



Hollywood Premier

Continued from page 1

toward the end, a spectacular, comic free-for-all that has influenced everything from *The Graduate* to *It's a Mad, Mad, Mad, Mad World* to *The Blues Brothers*.

The screening of *Girl Shy* will feature live musical accompaniment by the celebrated Los Angeles big band leader and pianist Mr. Dean Mora. In his many years as an orchestra leader, Mr. Mora has played for some of the biggest names in Southern California. His music is regularly played throughout Disney's California Adventure where it is heard by thousands of visitors each day. Mr. Mora and His Orchestra are also regularly featured at Maxwell DeMille's Cicada Club, a vintage night club and swing dancing venue in downtown Los Angeles as well as many other venues and events throughout Southern California.

Preceding the screening of *Girl Shy*, get ready to clap your hands and twirl your lasso with a fun-filled 1930s Western roundup with the

musical shenanigans of Will Ryan & the Cactus County Cowboys—featuring the Saguaro Sisters. It's "the King of the Radio Cowboys" and "the Band that Won the West"—featuring "the Sweetest-Sounding Trio West of the Great Divide!" A throwback to the lively music of yesteryear, Will Ryan & the Cactus County Cowboys will have you back in the saddle with a tuneful romp that will keep you whistling through the night. Will Ryan is a renowned voice actor and musician whose credits include many animated features, including *Mickey's Christmas Carol*, *An American Tail*, *The Land Before Time*, *The Little Mermaid*, and television's *Family Guy*.

This will be a fun-filled evening you will not want to miss!

Tickets are \$130. All proceeds support basic and clinical research into the causes, treatments, and cures for Parkinson's disease, dystonia, and other movement disorders.

For more information, or to purchase tickets, call 714-369-7426 or e-mail: pmdf@pmdf.org



Trauma-induced Dystonia

by April Ingram

If you happen to stop by the Lowe's Home Improvement store in Jackson, Tennessee you may learn more than how to complete your next DIY project. Johnny McCoy, a veteran of the US army and now a Lowe's employee working in the electrical department, is raising awareness about dystonia. McCoy has become an expert because the involuntary muscle contractions, repetitive movements and abnormal postures associated with dystonia started for him after he suffered a head injury while serving in the Tennessee National Guard. "People look at me like I've made up this crazy name for why my neck twists," McCoy told the *Jackson Sun*. "I am committed to changing this by sharing my personal

story to make people aware of what dystonia is and how it affects lives."

After telling people about his experience with dystonia, McCoy gives them buttons that say *Dystonia Moves Me* to stimulate other opportunities to discuss the disorder. He has given away more than 100 buttons and hopes that they will raise awareness about dystonia in the community, particularly about veterans who have dystonia as a result of service-related injuries.

Trauma-induced dystonia can sometimes appear after a physical injury to the body, including the head or brain, as it did for Johnny

McCoy. However, trauma-induced dystonia often goes undiagnosed because it can be challenging to identify. Doctors must rely on historical information or subtle characteristics of the symptoms because there are no specific diagnostic, radiologic (X-ray), serologic (blood tests), or other disease-related trademarks. If the injury occurs to the brain, then observable damage may be seen using neuroimaging techniques such as MRI scans. Additionally, symptoms often affect the side of the body opposite to the side of the brain injury.

Trauma-induced dystonia can sometimes be distinguished from primary or idiopathic dystonia because the symptoms may not respond to sensory tricks—physical gestures or positioning that can temporarily interrupt the unwanted movements. Moreover, trauma-induced dystonia may persist during sleep. Symptoms may also be paroxysmal, meaning that they occur in episodes rather than being constant. Linking dystonia to trauma is even more difficult because the symptoms may not appear for several months or even several years after the injury. Research has shown that certain factors may predispose a person to trauma-induced dystonia. These factors include the use of certain medications, coexistent essential tremor, prematurity at birth, and a family history of essential tremor or dystonia.

Given that traumatic brain injury can be a catalyst for the onset of trauma-induced dystonia, it is increasingly recognized as a significant problem among military service members. The Department of Defense has ongoing research activities in this area. Veterans’ advocates estimate that as many as 20% of veterans have experienced a traumatic brain injury

and the U.S. Department of Veterans Affairs estimates that post-traumatic stress disorder (PTSD) afflicts 10-20% of war veterans. Additionally, dystonia has also been noted as a serious side effect after long-term treatment with antipsychotic medications for PTSD symptoms.

A treatment that works for the vast majority of individuals with trauma-induced dystonia has not yet been found. Several oral medications have been used and shown some benefit either alone or in combination, including levodopa, trihexyphenidyl, clonazepam, and baclofen (oral and intrathecal especially for dystonia and spasticity). Botulinum toxin injections may be used to treat specific affected body parts, such as the neck, jaw, hands, or feet. Some surgical techniques have also been used for individuals who do not response favorably to medications—these include deep brain stimulation, the application of baclofen directly in to the area around the spinal cord, and the use of tiny electrical probes that are heated to destroy a small area of brain cells. Specialists recommend that while symptomatic treatment of pain and spasms with medication can be beneficial, early psychological evaluation and patient-specific treatment is important.

Common Types of Trauma-induced Dystonia	Has Occurred following...
Oromandibular dystonia (forceful contractions of the face, jaw, and/or tongue)	dental procedures
Blepharospasm (involuntary opening and closing of the eyes)	surgery or injury to the eyes
Cervical dystonia (forceful contractions, tightness or twisting of the neck muscles)	whiplash or other neck injury

Interview With Dr. Mohamed Salama—2014/2015 PMDF Grant Award Winner

by Mary Ann Chapman, PhD

What triggers nerve cell death in Parkinson's disease? That is the question Dr. Mohamed Salama is investigating in his laboratory at Medical Experimental Research Center (MERC) of Mansoura University in Egypt. Dr. Salama was one of the 2014/2015 PMDF grant award winners, and I asked him, via e-mail, to tell us a little bit about his research and background.

How did you get interested in movement disorder research?

I began my research journey in movement disorders when I was awarded a scholarship to study in Marburg, Germany. My supervisor was Professor Guenther Hoeglenger and our research focused on the underlying brain problems in Parkinson's disease. Upon returning to Egypt, I was awarded a big grant to work jointly with Professor Hoeglenger. Our goal was to develop a model to study the interplay between environment and genes in the development of Parkinson's disease.

How would you describe your research group in Egypt?

Following my return to Egypt, I realized that few people were interested in studying neuroscience. I therefore established the first Experimental Neurology Unit in Egypt, where I recruited students and began including them in research projects. I worked with several brilliant undergraduates and we were able to publish our findings in international journals and to present at professional conferences. Our research on strategies that protect nerve cells from dying in Parkinson's disease received several awards, including the best research in Egypt for the year 2013, the best presentation in neurology at the International Student Congress of Medical Sciences (ISCOMS) for 2012, and the Misr El-Kheir Foundation (MEK) international publications award for 2013. Following our success, many students have become interested in experimental neurology and our program has grown.

What aspect of your research are you most excited about?

I believe that unraveling the triggers and underlying



causes of movement disorders are the first steps to identifying effective treatments. That is what I am doing—trying to uncover the actual triggers that lead to movement disorders like Parkinson's disease. I am particularly interested in how the interactions between the environment and genes affect the disease process.

How will the PMDF grant money help you accomplish your research goals?

The PMDF grant will help support the first phase of our study, which involves a protein known as mTOR. The protein mTOR affects the cell's ability to degrade and eliminate other proteins and components it no longer needs. If these materials can't be removed, they can interfere with the cell's ability to function and can even lead to cell death. Our ultimate hope is that treatments that affect mTOR may eventually be useful for treating Parkinson's disease.

Wrestling with Restless Leg Syndrome

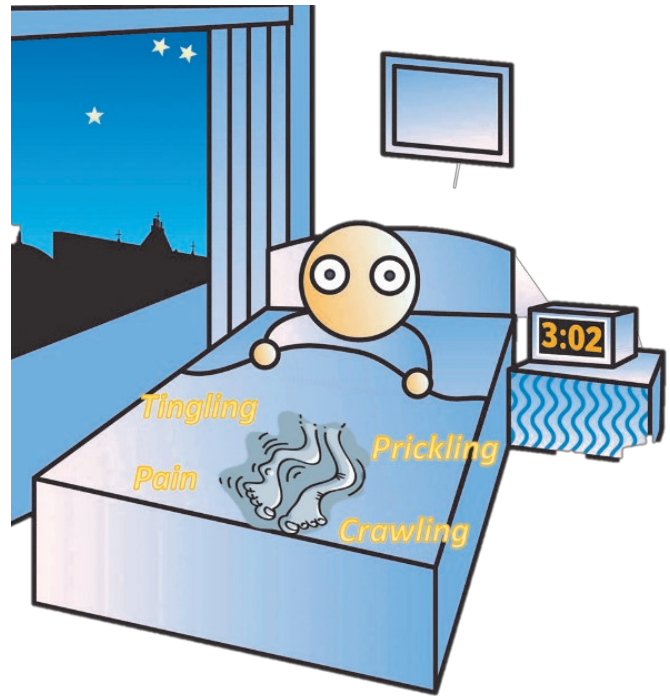
by April Ingram

Approximately 10% of American adults suffer from restless legs syndrome, a condition characterized by an urge to move their legs, usually because of uncomfortable sensations such as tingling, "pins and needles," prickling, crawling, or pain. These unpleasant symptoms usually begin about 15 minutes after lying down to sleep or relax, or after being sedentary for long periods such as during car or airplane travel. Although the leg sensations can be mild for some, they may be more intense and frequent for others, resulting in significant sleep loss, fatigue, and problems with daily activities.

Most people with restless leg syndrome also have involuntary or jerking leg movements, called periodic limb movements, during sleep. This can be disruptive to both themselves and their bed partner, resulting in fatigue for both. Periodic limb movements may also occur during the day, although most people simply move around when their legs begin to bother them, making daytime RLS less noticeable or troublesome. Recently, it has been found that these periodic movements are often linked to subtle breathing problems.

Restless leg syndrome has been classified into two main types: primary and secondary. Both have been linked to low levels of dopamine in the body. Dopamine is an important messenger in the brain that helps regulate many body functions, including thinking, behavior, mood, sleep, and movement. Low levels of dopamine can trigger the urge to move our limbs, as found in restless leg syndrome. But an extreme inadequacy of this hormone can cause tremors and the severe movements associated with Parkinson's disease. Primary restless leg syndrome has a genetic component stemming from a malfunction in the way dopamine is metabolized in both the brain and the body. Secondary restless leg syndrome may be caused by faulty iron metabolism, and iron has a key role in dopamine production.

Symptoms of restless leg syndrome can begin anytime in a person's life, even as early as infancy. Initially, symptoms may be mild and sporadic, but they typically get worse with age. After age 50, many people with this condition have daily symptoms and suffer from significant sleep loss. Restless leg syn-



drome can be triggered by pregnancy (usually after 20 weeks), iron deficiency, and certain medicines. In order to diagnose the condition, doctors will ask questions about the symptoms and also perform a physical examination to look for other possible causes for the sensations and need to move. A diagnosis of restless leg syndrome is typically based on four criteria:

- Sensations of tingling, "pins and needles", prickling, crawling, or pain.
- The sensations and the urge to move begin or get worse during periods of rest or inactivity, such as sitting or lying down.
- The sensations and the urge to move are partially or totally relieved by movement, but relief may be temporary and only last while walking, stretching, or moving.
- The urge to move and the sensations are worse in the evening or at night, although some people may have severe sensations and urges to move throughout the day and night.

Restless leg syndrome often goes undiagnosed because people don't seek medical attention. In some cases, physicians may not recognize the condition and may believe that the symptoms are caused by other ailments, such as insomnia, stress, muscle

cramps, or arthritis. A sleep study technique called polysomnography may be performed to help doctors diagnose restless leg syndrome and rule out other sleep disorders. This test records the electrical activity of the brain, eye movements, muscle activity, heart rate, breathing, air flow through both the nose and mouth, and blood oxygen levels. Although this test is not essential, it provides details of limb movement symptoms and can help to evaluate the severity of symptoms.

If restless leg symptoms are mild, a doctor will often recommend a few lifestyle changes that may be helpful, such as avoiding tobacco, alcohol, and caffeine;

regular exercise; massage; heat or ice; and making the sleep environment more comfortable. For more severe cases, medications may be useful to help control urges, dull unpleasant sensations and improve sleep. Mirapex® and Requip® are two drugs approved in the United States specifically for the treatment of restless leg syndrome. They were originally developed for treatment of Parkinson's disease and work by increasing the activity of dopamine. These medications may relieve some of the symptoms, which may improve sleep, but side effects have been noted. It is always best to fully discuss the pros and cons of all treatments with your doctor.

Zent-a-Thon Walk/Run Fundraiser





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OUR MISSION

To support basic and clinical research into the causes, treatments and cures for Parkinson's disease and other movement disorders such as dystonia, myoclonus, spasticity, and tremor.

The Parkinson's and Movement Disorder Foundation is committed to working with other organizations that have similar philosophies in an effort to bring together expertise from both basic and clinical science perspectives.

We are dedicated to enhancing the quality of life for those who suffer from movement disorders and their families, through research, education, and community outreach.